Core Competences in Genetics for Health Professionals in Europe

01 - Executive Summary

The use of genetics and genomics within a wide range of health care settings requires health professionals to develop expertise to enable them to practise appropriately. There is a need for a common minimum standard of competence in genetics for health professionals in Europe. Development of expertise is dependent upon education, training and experience of the health professional involved.

It is acknowledged that there are significant differences in the way in which professional education is delivered and practice is regulated across the countries of Europe. While a minimum standard for practice is required, setting curricula is not viewed as a practical way of ensuring those standards are met, given the differences in systems. The establishment of core competences is currently being used as a basis for health professional education in many other fields and settings (Walton & Elliott, 2006; Wold et al, 2006; Smith, 2005). It was therefore agreed by the Expert group of the EuroGentest project Unit 6 that a pragmatic and workable solution would be to describe and agree, by consensus, a set of core competences that could apply to health professionals in Europe, whatever their national setting. This could provide an appropriate framework for establishing minimum standards of preparation for health care professionals in genetics across national boundaries.

A background document is provided and the core competences are presented in two separate documents: i) for those professionals whose specialisation is in genetics and ii) for those professionals who are generalists or who specialise in an area of health care other than genetics. Within each section, the competences for the groups of professionals who are most likely to be involved in offering genetic healthcare (medical doctors, nurses, midwives, scientists) are identified. The core competences have been based upon existing frameworks developed in a number of countries for a range of professional groups. These have been discussed and modified for the European context. It must be emphasised that in each case *the recommendations have been based on work involving consultation with the particular group of professionals involved.*

The set of core competences for each main group of professionals is included at the end of this Executive Summary, but readers are advised to refer to the full documents that include both competences and suggested learning outcomes [http://www.eurogentest.org/unit6/].

The goal of this work is not to unify the existing genetic services across national boundaries, but to achieve broad consensus about a coherent set of standards to guide the education of health professionals.

For the purpose of this document, competences are defined as the set of behaviours that are expected by independent professionals (Plasschaert et al, 2002). The competence therefore describes the behaviour expected by the professional in the particular setting in which he or she works. Learning outcomes are used to dissect the competence into more manageable units that can be the focus of learning. Each learning outcome encompasses particular knowledge, skills or attitudes. In turn the learning outcomes can be used as a basis to build a curriculum. The curriculum should include the information and opportunity for skill development to enable the student or trainee to acquire the necessary knowledge, skills and attitudes to work competently. We are aware that in many countries there are curricula that have been devised to educate and train health professionals in genetics. These curricula could be assessed against the competences and learning outcomes for particular groups of professionals, to ensure that all the requisite areas are covered.

The EuroGentest Unit 6 project team is actively seeking input and would be willing to meet with professional and patient groups in different countries to receive feedback and to support development of competences that are applicable to the local and regional situation. All aspects of the core competences have been developed with consideration of the policies of the European Society of Human Genetics Public Policy Committee and support those policies.

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References

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Brief list of suggested competences for specific groups of health professionals

A. Generalists and those specialising in a field other than genetics

General practitioner

1. Identify individuals who may have or may carry a genetic condition.
2. Communicate information about genetics in an understandable, comprehensible and sensitive way, helping patients to make informed decisions and choices about their care.
3. Manage patients with genetic conditions, using accepted guidelines.
4. Obtain specialist help and advice on inherited conditions.
5. Co-ordinate care with other primary care professionals, geneticists and other appropriate specialists.
6. Offer appropriate psychological and social support to patients and families affected by a genetic condition.

General nurse/midwife

1. Identify individuals who might benefit from genetic information and services.
2. Tailor genetic information and services to the individual's culture, knowledge and language.
3. Uphold the rights of all individuals to informed decision making and voluntary action.
4. Demonstrate knowledge of the role of genetic and other factors in health and disease.
5. Demonstrate a knowledge and understanding of the utility and limitations of genetic testing and information.
6. Recognise the limitation of one's own genetic expertise.

Medical specialist in fields other than genetics

1. Identify individuals with or at risk of a genetic condition.
2. Communicate information about genetics in an understandable, comprehensible and sensitive way, helping patients to make informed decisions and choices about their care.
3. Be familiar with the uses and limitations of genetic testing and be able to use genetic testing appropriately
4. Manage patients with genetic conditions, using accepted guidelines.
5. Obtain specialist help and advice on inherited conditions, as appropriate.
6. Co-ordinate care with primary care professionals, geneticists and other appropriate specialists.
7. Offer appropriate psychological and social support to patients and families affected by a genetic condition.

Specialist nurse, specialist midwife and specialist allied health professional

1. Identify individuals who might benefit from genetic information and services.
2. Tailor genetic information and services to the individual's culture, knowledge and language.
3. Uphold the rights of all individuals to informed decision making and voluntary action.
4. Demonstrate knowledge of the role of genetic and other factors in health and disease.
5. Demonstrate a knowledge and understanding of the utility and limitations of genetic testing and information.
6. Recognise the limitation of one's own genetic expertise.
7. Obtain and communicate credible current information about genetics for self, clients and colleagues.

Specialist dentist

1. Identify patients with a genetic condition and recognize the orodental manifestations of these rare diseases.
2. Communicate information about genetics in an understandable, comprehensible and sensitive way, helping patients to make informed decisions and choices about their care.
3. Manage patients with genetic conditions, using accepted guidelines.
4. Obtain specialist help and advice on inherited conditions, as appropriate.
5. Co-ordinate care with primary care professionals, geneticists and other appropriate specialists.

6. Offer appropriate psychological and social support to patients and families affected by a genetic condition.

B. Specialists in genetics

Clinical geneticist

1. Identify individuals and families whose disorder or condition is determined, partly or fully, by a genetic component.
2. Determine the accuracy of the clinical diagnosis and, if needed, initiate additional clinical examination to make an exact diagnosis.
3. Be familiar with the feasibility and accessibility of genetic services that could help individuals and families through genetic counselling.
4. Provide an accurate speciality-focused view on the nature of a genetic disorder.
5. Determine the need for and utility of genetic tests relating to a disease or special condition.
6. Understand the meaning of genetic test results and translate those results into practical disease-specific information for both patients and other professionals.
7. Help individuals and families to understand the information provided during genetic counselling.
8. Facilitate understanding between individuals, families, their family doctors and specialists about genetic disorders, test results, and inheritance patterns.
9. Determine the risk of occurrence or recurrence of a disease or condition.
10. Understand the genetic and environmental components of common diseases.
11. Provide genetic information that helps individuals or couples make informed reproductive decisions.
12. Work within the boundaries of ethical practice.

Genetic specialist nurse or genetic counsellor

1. Establish relationship and clarify the counsellee's concerns and expectations.
2. Make appropriate and accurate genetic risk assessment.
3. a. Convey clinical and genetic information to counsellees, appropriate to their individual needs.
3.b. Explain options available to the counsellee, including the risks, benefits and limitations.
3.c. Evaluate the understanding of the individual related to the topics being discussed.
3.d. Acknowledge the implications of individual and family experiences, beliefs, values and culture for the genetic counselling process.
4. Make an assessment of counsellees' needs and resources and provide support, ensuring referral to other agencies as appropriate.
5. Use of a range of counselling skills to facilitate counsellees' adjustment and decision-making.
6. Document information including case notes and correspondence in an appropriate manner.
7. Find and utilise relevant medical and genetic information for use in genetic counselling.
8. Demonstrate ability to organise and prioritise a case load.
9. Plan, organise and deliver professional and public education
10. Establish effective working relationships to function within a multi-disciplinary team and as part of the wider health and social care network.
11. Contribute to the development and organisation of genetic services.
12. Practice in accordance with an appropriate code of ethical conduct.
13. Recognise and maintain professional boundaries and limitations of own practice.
14. Demonstrate reflective skills and personal awareness for the safety of individuals and families.
15. Present opportunities for clients to participate in research projects in a manner that facilitates informed choice.
16. Demonstrate continuing professional development as an individual practitioner and for the development of the profession.

Molecular geneticist

1. Work independently in the molecular genetics testing laboratory.
2. Perform a range of genetic tests for the purposes of diagnosis, ascertainment of carrier status and predictive testing.
3. Interpret the results of genetic tests that are performed.
4. Provide information to health care professionals based on both the results and interpretation of the results.
5. Participate in clinical research and in the introduction of new methods.

Cytogeneticist

1. Work independently in the cytogenetic laboratory.
2. Work proficiently in the cultivation of cells for both prenatal and postnatal chromosomal examination, processing of cells, preparation of slides and karyotyping.
3. Interpret the results of cytogenetic and molecular cytogenetic findings.
4. Provide information to health care professionals based on both the results and interpretation of the results.
5. Participate in clinical research and in the introduction of new methods.

Biochemist Geneticist/Biomedical scientist

1. Work independently in the biochemical laboratory.
2. Carry out biochemical testing related to diagnosis and management of genetic disease and carrier states, especially related to inborn errors of metabolism.
3. Interpret the results of biochemical tests.
4. Provide information to health care professionals based on both the results and interpretation of the results.
5. Participate in clinical research and in the introduction of new methods.